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ABSTRACT

A task force approach to care of profoundly retarded children includes parent counseling services. Counseling is usually limited to initial interviews in which the psychologists must explain the diagnosis, teach parents to accept the child's maturity age as the best gauge of his ability, and make parents aware that their child will require constant care. As counseling is so limited, the psychologist must plan for the child in terms of initial family attitudes, whether these include belligerence, denial, depression, guilt, apathy, or rejection. Psychologists should deal with these attitudes by allowing parents to vent hostility, by discussing state services that can alleviate the burden of total care, by informing parents of various causes of profound retardation, by convincing overprotecting parents that their child can be trained to achieve some degree of independence, by showing rejecting parents how to include the child in family matters, and by assisting parents to accept their child's intellectual status. Clinicians must be alert to factors (such as cultural or experiential deprivation, autism, or undetected hearing loss) which may cause an appearance of profound retardation. Difficulties in working with children suspected of profound retardation, including hyperactivity, withdrawal, lack of speech, or belligerence, can often be overcome by allowing the child to play and interrelate freely with his parents until he feels comfortable in the diagnostic setting. (GW)

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A TASK FORCE APPROACH TO SERVING PROFOUNDLY RETARDED CHILDREN AND THEIR PARENTS

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The very size of Chicago makes it imperative that there be areas of decentralization within the Chicago Board of Education. Extremes of opinions indicate that there is either not enough or too much decentralization, and there are merits to both points of view.

Decentralization involves the division of the city into three units, each with its own administrative personnel. In each unit there is a Director of Pupil Personnel and Special Education under whose aegeis Task Force school psychologists fall. The Director of Pupil Personnel and Special Education has the responsibility for the education of every school age child in her area.

The School Code of Illinois makes it mandatory that the Chicago Public Schools provide an education for all handicapped children. The Code also provides that the public schools may pay tuition in private schools which are non public for students whose disabilities are too complex or too severe to attend even special programs in the public schools.

Since summer of 1972, the Chicago Public School System has attempted to provide such special education facilities as may be needed by each handicapped child from the ages of 3-21. It is these children who are the special concern of Task Force. The children assigned to Task Force fall into these categories:

1. Children who are profoundly retarded, i.e. IQ below 35 and who require custodial care and/or intensive training.

2. Children who are too emotionally disturbed and cannot function in a classroom environment.

3. Children who are multiply handicapped.

Should the special educational facilities of the school system be unable to meet the needs of a specific child because of the severity of his handicapping condition, the school system may elect to provide tuition reimbursement to enable the child to attend a state approved private facility which can provide for his needs. Maximum reimbursement is $2,000 annually--the last $1,400 of which is paid by the state.

A child in this category generally has been determined to be too retarded to benefit from a program for the trainable mentally handicapped or so mentally ill or learning disabled that the program required is not possible in a public school. Therefore:

1. tuition reimbursement is obligatory on the part of the participating school system; and

2. tuition reimbursement is for the child who CANNOT BE trained or taught in any program required under mandatory legislation.

In most instances, eligibility for tuition reimbursement can be established only after trial placement in public school with special education service.

Referral of all handicapped children is made first to the local school principal. Following this referral, information is forwarded to the Task Force. The Task Force consists of the following personnel: Two Psychologists, Two

Social Workers, and Two Teacher-Nurses.

During the past two summers, the Task Force has been expanded to include an Educational Clinic for the purpose of differential diagnosis in terms of the child's school, social, medical, and general needs. Personnel added include Pediatrician, Teacher-Nurses, Speech Therapists and Teachers. This Clinic began to function on an on-going basis beginning the fall of 1971.

Procedure involves the initial registration of the child in the neighborhood school. At the time of registration, medical consent forms are obtained and the Teacher-Nurse assigned to Task Force immediately requests all pertinent medical information. The registration form and the request for individual psychological examination are routed through the Area Director of Special Education to the Task Force Psychologist. After administration of psychological examination and determination of the child's capabilities, potential, and needs, Task Force meets for staffing in order to integrate and consider all data available on the child, and to plan for the child's school needs. Staffings include all Task Force Personnel and the Area Consultants of Psychologists, Social Workers, and Teacher-Nurses. Often the Director of Special Education also participates.

Counseling parents of the profoundly retarded child presents one major difficulty in that counseling is usually limited to the initial interviews. We know that the parents

rarely return for follow-up consultation although psychologists are available. It is important that the parents receive as much information about this child as they can absorb at the time. A diagnosis must not only be made, but it must be imparted to the parents and explained in terms with which the family is familiar and which is acceptable to them. Often imparting the diagnosis can take as much skill as administering and evaluating the psychological data. The psychologist must keep in mind the fact that hearing this diagnosis is one of the greatest hardships a family may have to bear.

Profoundly retarded children represent a very small percentage of the entire population. Yet the needs of this group may be sometimes greater than any other group. Generally their life span is shorter, they are subject to more illnesses and physical defects. Few of them, if any, will be able to care for their own needs. We know, however, that parents generally love their exceptional child even as they do their normal children. During infancy, this child may not have appeared too much different from other children. The differences, though, become more obvious as the child grows older.

When the parents come for psychological evaluation for the first time, the psychologist must show unusual sensitivity in dealing with this family. We try to meet the needs of the parents initially by answering the questions they bring to us. How does he compare with other children? What can they expect

of him? How will he fit into the family? How can they help him? What are the training methods to use? Will the school help him? Will he ever function like other children?

In discussion with the parents, we point out that the more retarded the child is, the less he is like other children especially as he approaches school age. We attempt to teach the parents how to accept the child's maturity age as a better gauge of what he is really able to do. We try to get away from the concept of chronological age and show the parents that this is an idea which is unrealistic in dealing with a profoundly retarded child. This helps the family make concrete plans for the youngster by training him to work up to his own expectation level rather than that of his chronological peers.

Any plan for the handicapped child must take into account both his pre-school and post-school years, unless he is to be placed in a residential setting. Parents must be made aware of the fact that their child will never be self-supporting. He will require constant care and supervision. This means that in the case of older parents, some other family member might be expected to provide for this child. Parents might wish to explore the possibility of lifelong support by a governmental or private agency when they are apprised of the fact that the profoundly retarded child will always require a directed life program.

In planning with the parents, consideration must be given to the feelings they are experiencing at the time

regarding the child's placement. As counseling cannot be on an on-going basis with the family, the psychologist must accept the attitude of the parents at the time and attempt to plan for the child within that framework. For example, the resigned or apathetic parents are much more amenable to placement than the parents who deny anything is wrong with their child. However, these parents may be so accepting and so resigned, that they have completely ceased any efforts to help or train the child. In such event they must be made aware of what they can do to help their child and what they can and should expect of him.

We see many belligerent or depressed parents who bring their children to us for the first time. Generally, if the belligerent parent is permitted to ventilate his hostility at the beginning of the session, he is calm enough to discuss the child's placement. Frequently the anger he is ventilating has been suppressed for a long time because the parent has not been able to get as angry at the severely retarded child as he would were the child more normal. Accepting the fact that the parent of the special child may be more justified in his belligerent attitude is important for the school psychologist if he is to handle school placement at this initial interview.

We must also accept with understanding the parents who feel depressed in this same situation. Offering the family some sort of relief from total care of the child frequently

lifts a great burden from the parents. When they realize that the child will be in a secure environment in a daily school program, we see parents leave with much more hope than when they came. For some families the thought of constant care and supervision for this child for a number of years has been a tremendous worry--knowing that the State can offer some relief produces remarkable changes in parental attitude.

The parents who feel guilt for having brought this exceptional child into the world is another aspect of the problem. Self-guilt is destructive both to the parents and to the child. The role of the psychologist is to inform the parents of some of the reasons which may have caused profound retardation which are unrelated to genetic factors or personal feelings and traumatic events. This may also serve to reassure the parents. Should the guilt feelings be so obsessive that they over-ride other factors and color the day-to-day relationships within the family, it may be advisable to direct the family for counseling.

Sometimes the feeling of self-guilt is displayed in over-protection of the profoundly retarded child. In these families, the child is not permitted to learn even the rudiments of self-care or to achieve to the limits of his own potential. The parents have created a distorted image that imposes upon them the need to serve this child, and care for him. They feel they must sacrifice themselves for having

brought this child into the world. Here the psychologist must intervene and convince the parents that this child must be trained to achieve some degree of independence.

Parents who completely reject the exceptional child are another group to consider. These parents may never include their child in family activities. In conversation their special child is never mentioned. Milestones in this youngster's life, areas of development, and special skills are never noted or remembered. The parents themselves may be unaware of their overt behavior and if confronted, may deny that the situation exists. The psychologist must be prepared to point out these areas of difficulty to the parents and emphasize ways they might include the child in family matters within reasonable limits, and not at the expense of other family members.

When parents come to the Clinic, they come knowing that something is wrong with their child whether they are able to verbalize this on a conscious level or not. In many instances the family is convinced that their child will "outgrow it" or needs time to catch up with the other children in the neighborhood. The psychologist must be cautious in pointing out that this child may never "catch up." Perhaps denial is the only way the family has of coping with this child and his needs on a day-to-day basis. Until the family is able to accept the reality of the child's status, they cannot effectively alter the environment to meet their youngster's specific needs.

Parents who may themselves be retarded are unable to properly train and stimulate their child to maximum growth. Dealing with these parents presents the greatest challenge to the clinician because the family's capacity for understanding the changes which must be initiated is very limited. In this instance the family may require the on-going services of the social worker to direct them to more effectively deal with their handicapped child.

In the large metropolitan community children from all backgrounds are funnelled into the school system and may be brought to the attention of the school psychologist. The clinician must be alert to factors which may cause an appearance of profound retardation. These factors are caused by the varied ethnic and multi-cultural society in which we live. Each individual family unit and larger social group places emphasis on the immediate needs of its own structure. One group may concentrate its energies and resources towards intellectual striving and achievement. Another group may emphasize the existing social structure and its need for order and conformity. A group may shelter and seclude itself from the larger society and thereby isolate itself from stresses and tension. Or there may be the group where the very struggle for economic survival precludes the dispersion of energies to any other aspects of living. Thus the psychologist must be aware of influences which require careful screening to rule out seeming retardation.

We recall the eight-year-old girl whose parents registered her as a handicapped child for the first time. The parents explained that the child did not speak and, therefore, they had hesitated to enroll her previously. The child appeared interested in her environment. Observing her at play, it was noted that the play was constructive; attention was good; no distractibility was noted. In the examining room as effort was made to administer intelligence tests, it appeared that the child constantly tilted her head to one side. Her eyes did not turn away and her attention appeared riveted. You might say it would appear that this child could be suspected of hearing deficit. Yet how often have we erred by not realizing the existence of a hearing deficit. This child was eight and had routine medical examinations. Undetected hearing loss may be incorrectly diagnosed as profound retardation or emotional disturbance.

It is not unusual for us to evaluate a child who has had no experiences with the materials which are presented. This child's background may be one of complete neglect in terms of any needs but the ones of physical survival. Cultural deprivation--yes! Experiential deprivation--yes! But profound retardation? Can this diagnosis be made with certainty? The role of the psychologist then becomes one of determining from other than testing, the potential which the child may have. Can the child learn by example? If a small

puzzle is presented and demonstrated - can the child learn from observation? Can he copy? How about his memory skills? What plan for this child can and should be recommended? A school for profoundly retarded children may only continue a pattern which has been established rather than elicit potential to and motivate the child.

The child of retarded parents may simulate retardation as a result of lack of stimulation and training. A recent California study has indicated that the pattern of retardation could have been altered by early intervention. In evaluating this youngster the psychologist must ascertain the inherent ability and the response of the child when opportunities for learning are presented.

The autistic child indicates to us the extremes and effects of emotional disturbance. Children who appear profoundly retarded may have chosen their form of protection from the environment which they found unacceptable or with which they were unable to cope. This child has withdrawn to his shelter and his world. The child needs help but can he receive the kind of therapy which he requires in a school for profoundly retarded children? Our evaluation of this child will determine the direction in which he will go. What are some of the clues which may direct us to the proper diagnosis? The observed relationship between parent and child; the manner of play; the approach to strangers; parental report of early development; sibling inter-relationships; and, of course, the child himself in the testing situation. Is

there complete withdrawal? Are rest items answered erratically? Can the child pass difficult items, yet fail lower levels? The evaluation of answers as recorded and carefully made investigation of all clues is a must before proceeding on to any educational plans for the child.

As the psychologist begins to work with the child who is suspected of profound retardation, many problems immediately become apparent. The difficulties presented include: extreme hyperactivity, or complete withdrawal; lack of speech, indistinct speech or incessant babbling; and belligerence and wilfulness.

The pattern which we have established in our office is to permit the child and parent to interrelate initially in complete freedom. The child is directed to toys which have been placed in one area of the room. The parent and the examiner sit at a table to discuss the problem from the parent's point of view. The child at play is observed. Should he wander about the room, the examiner permits the parent to re-direct the child. If objects are thrown about, our focus is on the manner in which the parent disciplines or perhaps does not discipline the child. Does the child come to the parent frequently? Can the child amuse himself?

By the time the psychologist is ready to work with the child, the child usually feels comfortable and at ease. After two years we can still count on the fingers of one hand, those few children who have refused to leave the parent and "play" with the examiner.

Our procedure in testing is to initially present the Stanford-Binet Scale. When the child is unable to succeed at the two year level, we turn to the Cattell Infant Intelligence Scale. It has been our experience that these two instruments provide us with good tools to evaluate the youngsters we see. Of course, we complement these instruments with Peabody Picture Vocabulary, Bender Gestalt, Vineland Social Maturity Scale, and other instruments. When we are confronted with a hyperactive child, we often find ourselves imitating hyperactivity of the youngsters we are testing. The speed with which we attempt to present our test items would if photographed be a caricature of early movies. The great difficulty which we encounter is the presentation of the Cattell items which are not as well organized or as limited in quantity as the Binet.

It is not unusual for the psychologist to emerge from a session with a youngster with bruises resulting from blocks and toys that have been thrown and punches well directed. Often we find the solution to these youngsters is to hold them firmly on our laps, as we proceed to demonstrate our test items.

At the other extreme, the child who is withdrawn or timid presents a different problem. Our approach to him is more cautious and requires more subtle handling. Often we ask the parent to escort the child into the testing room and after a few games, the parent may be able to leave. If not, the parent is requested to watch silently as items are presented.

The child who is negativistic and repeatedly says "no" poses the problem of whether the negative response is due to instability or merely an assertion of his will in a battle with the stranger. We have found it expedient to accept the no and to direct the child to other channels--milk, cookies, candy. After a short break, we proceed again. At times we are successful. On other occasions we must conclude that the present intellectual functioning of the child could not be determined.

As we have worked with these children and families, we have slowly become alerted to other problems and in some instances have been able to alter the direction of family depression and despair into one of hope. True, these may not be frequent occurrences, but if we have succeeded in properly identifying problems that can be helped, situations that can be altered in only a few of the many children we have seen, then we have achieved our purpose.